

# Real lives on paper plans

Citation for published version (APA):

Herps, M. (2017). *Real lives on paper plans: individual support planning for people with intellectual disabilities*. [Doctoral Thesis, Maastricht University]. Maastricht University.  
<https://doi.org/10.26481/dis.20171026mh>

**Document status and date:**

Published: 01/01/2017

**DOI:**

[10.26481/dis.20171026mh](https://doi.org/10.26481/dis.20171026mh)

**Document Version:**

Publisher's PDF, also known as Version of record

**Please check the document version of this publication:**

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

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## VALORISATION

This thesis aimed at getting a better understanding of working with Individual Support Plans (ISP) for people with intellectual disabilities (ID) in The Netherlands. The studies that were conducted add to the understanding of ISP in our country and more specifically they offer information for the enhancement of ISP policy and practice. The study outcomes may help improve the effectiveness of working with ISP in support services and agencies. This chapter focuses on opportunities for valorisation and describes actions that already have been taken to disseminate the knowledge gained in the present research project.

## RELEVANCE

If a person needs to use professional support in his or her life, it is necessary to determine the type and intensity of support that is required and to make agreements on how and by whom the support is being provided. As such, ISP is a core element of everyday service provision to people who need long-term care. Moreover, ISP is a legal requirement and as such relevant for many thousands of people in the Netherlands. The legal requirement reaches a wide population, and ISP is not only relevant in supporting people with ID, but also in the care and support of elderly and people with psychiatric problems.

However, even though it is such a wide-spread and widely used instrument, little is known about how ISP works. Its usage is based on assumptions and beliefs rather than on empirical evidence. The present studies probe into critical and empirical analysis of ISP practices and formulate conditions that are favourable or unfavourable for their effectiveness.

Finally, service provider organizations spend a lot of money on the development and implementation of ISP documents and to integrate ISP documents in digital systems. Therefore, they should carefully consider what would be beneficial to the use of ISP and what can be done to make ISP of more value for clients, staff and the organisation.

## TARGET GROUPS

### People with ID

This thesis has shown that active and meaningful involvement of service users is not self-evident, and requires thoughtful and personal approaches. As we found out in our study described in chapter 3, people with ID are not fully aware of the function, roles and responsibilities regarding ISP and of how ISP may help them in their life. The results of this thesis serve

as an entrance for providing better information to people with ID. The recommendations that were made may help people with ID to take advantage of their ISP as an opportunity to increase participation in their support process and to empower them to being partners in the process.

### **Professionals working with people with ID and their management**

Service providers develop their own ISP forms and procedures and support staff usually is responsible for having ISP meetings with people with ID and their relatives, to develop the ISP document and to follow up on the agreements that are made. They have to find a way to manage the difficulties that are described in this thesis, e.g. balancing the different expectations that exist regarding ISP, such as it being a tool for enhancing person-centered support whilst also being used in the context of quality and accountability. However, improvement is possible in downsizing the ISP document and involving the person with ID, and chapter seven describes different practical implications and recommendations.

### **Policy makers on both regional and national level**

The studies addressed in this thesis showed that policy makers influence ISP procedures and content in such a strong manner; that it is questionable how reliable ISP document are in assessing the quality of care. For example, our study on sexuality in ISP document showed that even though reference regarding sexuality was found in almost all ISP documents – because ISP templates include the subject – the actual ISP was hardly providing information about the current support needs of that person nor about related support agreements. Having boxes ticked does not equal good quality care.

## **PRODUCTS AND ACTIVITIES**

Different products and activities have been envisaged to disseminate the gained knowledge. This paragraph describes these products and activities.

### **Products**

The results of the study in chapter 2 were described in the document “*Handreiking Ondersteuningsplannen 2013*”, summarising the state of art on ISP in The Netherlands. This document was sent to all member organizations of the Dutch Association on Disability (VGN). Based on this document, we also published a “*kennisbundel*”, for teachers to be used in educating people who will be going to work in the field of ID (Herps, 2014<sup>1</sup>).

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<sup>1</sup> Herps, M. (2014). Kennisbundel voor docenten Zorg & Welzijn. Ondersteuningsplannen. Utrecht: Vilans, Trimbos instituut, V&VN, Calibris.

We developed an easy-to-read brochure and made a short video about the research project described in chapter 3. The brochure and video were sent to all participants of the study.

These products are freely accessible from the website [www.kennispleingehandicaptensector.nl](http://www.kennispleingehandicaptensector.nl). This website is targeted at direct support staff working with people with disabilities in the Netherlands. Individual support planning is one of the themes and the author of this thesis is responsible for the content on this page. It contains both insights from our research as well as good practices, examples of ISP in different organizations, tools that staff can use freely and other relevant information on ISP.

### Activities

The study in chapter 2 was conducted during a nation-wide ISP improvement project in which service provider organizations participated. A total of 28 organizations all over the Netherlands participated in this project. During this project, project teams of these organizations met during three one-day meetings. Between these meetings, we contacted the project leaders by email and telephone to check on their progress. This project gave us a better understanding about the difficulties organizations face in ISP and we were able to disseminate the knowledge from our research in this group.

Furthermore, knowledge that was developed during this thesis is implemented in service provider organizations that ask for support and advise in developing and implementing or improving and implementing their ISP procedures and content. In this role, we usually work together with direct support staff and people with ID to develop an ISP that fits their needs, advise on the electronic client record and help implementing the new ideas.

## INNOVATION

The problems addressed in this thesis and the research approach that was applied have been strongly practice-based. Incorporating the perspectives of people with ID, of staff, service providers and policy was needed to address the complexity of ISP. It has shown that problems with ISP manifest themselves on the work floor, but are also found in organizational and policy levels. This means that improving on these issues requires involvement on all of these levels. The main focus of this thesis has always been the person with ID, and how ISP can help him or her in their life.

